Defining inclusive and community research

Working definitions

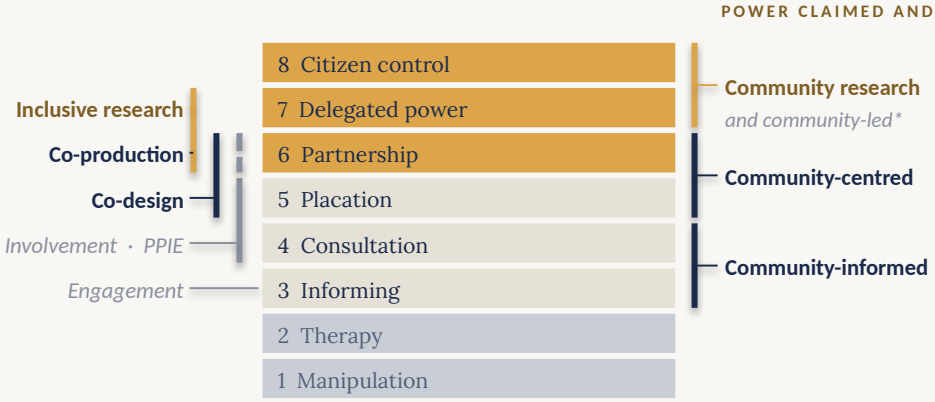
THE THREE QUESTIONS

Every term on this sheet takes a position on power. These three questions show which one you are looking at.

01 Who holds the resources?	02 Who makes the decisions?	03 Whose outcomes are prioritised?

Place a project by who holds these three, whatever its method or its label. A survey that a community organisation designs and controls can be community research. A workshop an institution controls does not become co-production because it carries the name.

ONE LADDER, TWO SIDES



*Arnstein's ladder of citizen participation (1969) in the middle, read two ways. Our terms (bold) are placed by their definitions; sector terms (grey italic) by where they most often show up in practice, dotted where they can reach. *Community-led sits at the top only when communities hold all three.*

OUR WORKING DEFINITIONS

Inclusive research

Steps 6 to 7

An equity-centred, partnership-based approach to generating knowledge that restructures who participates, how decisions are made, and whose knowledge counts.

Equity-centred means changing the structural conditions under which people take part. At its best it reaches delegated power: communities lead a whole workstream, while the institution holds the award.

Resources: a research organisation, shared. Decisions: shared at each stage. Outcomes: shared priorities.

Co-production

Step 6

A partnership in which communities and researchers share decisions, resources and responsibility across the whole research life cycle, recognising community knowledge as equal to academic expertise.

In line with NIHR's co-production guidance, where everyone's knowledge is "afforded equal respect and value" (2021).

Resources: shared, at least in part. Decisions: shared at every stage. Outcomes: agreed together.

Co-design

Steps 5 to 6

Communities and professionals designing something together, with communities sharing power over how it is designed, though not necessarily over what happens next.

In the literature, co-design usually means a creative process at the design stage (Vargas et al., 2022).

Resources: the institution. Decisions: shared, inside the workshop. Outcomes: not necessarily theirs.

Community research

Steps 7 to 8

Research that starts from community experience and priorities, with people affected leading the research and deciding how resources are used.

Power claimed and held: the community organisation holds the funding. Much of the sector calls this community-led research.

Communities hold all three.

Community-centred

Steps 5 to 6

Research centred on community experience, with people affected delivering the research and influencing how resources are used.

It has real value. Much of what is called peer or community-led research sits here. Public health uses the term more broadly (South, 2015).

Resources: influenced. Decisions: shared, at best. Outcomes: often the institution's.

Community-informed

Steps 3 to 4

Research that seeks the views of communities affected by the issue under study, with the institution leading the research and deciding how resources are used.

Often called community-engaged research, a wider term that runs from outreach to shared leadership (Principles of Community Engagement, 2011).

Resources, decisions and outcomes: the institution.

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THE SECTOR'S TERMS: CHECK WHICH ONE YOUR PARTNER MEANS

These are not our definitions. Their meaning depends on who is speaking, so check which one your funder, team or partner means, write it down, and agree it at the start. In NHS England's words, these terms "often overlap, mean different things to different people".

TERM	WHAT NIHR MEANS	WHAT OTHERS MEAN
Engagement	"Where information and knowledge about research is provided and disseminated" (NIHR Briefing notes, 2021, updated 2024).	A two-way process (NCCPE). An umbrella that runs all the way up to co-production (NICE NG44, 2016; NHS England, 2022).
Involvement (PPI)	Research carried out "with" or "by" members of the public, rather than "to", "about" or "for" them.	Level 3 of 5 on the IAP2 spectrum used by many councils. In NHS law, the duty to involve can be met by consulting people or giving them information (NHS Act 2006, s.14Z45).
Participation	Taking part in a research study.	Taking part in decisions (NHS England, 2022). For Arnstein (1969), "a categorical term for citizen power".
PPIE and its cousins	PPIE, PPIEP, CEI and now public partnerships. Their scope varies between NIHR centres: some add participation, some do not.	PPI is exposed "to criticisms of exclusivity and tokenism" (Ocloo and Matthews, 2016).
Research inclusion	An NIHR condition of funding since November 2024: inclusion designed in from the outset, as a costed part of the award.	About who takes part. On its own, it does not settle who decides.

On the ladder, engagement most often sits at informing, and involvement and PPIE at consultation and placation, reaching partnership in their best-resourced forms.

FROM YOUR SEAT

Funders

When you assess a bid.

1. **How much of the award goes to communities?**
   Look for a costed community line, shown as a share of the award.
2. **How much say will they have over how it is used?**
   Look for a decision plan, stage by stage.
3. **Whose ideas is it built on?**
   Look for communities shaping the questions, and findings going back to them.

Researchers

When you design a bid.

1. **What share of the budget goes to community partners?**
   Cost it in the first draft, line by line, with their overheads.
2. **Which decisions will communities make, and when?**
   Write them into the plan, stage by stage, with how you will settle disagreement.
3. **Whose questions are these?**
   Shape them with communities before you write. Name community researchers as authors.

Community organisations

Before you say yes.

1. **What share of the budget comes to you?**
   Your own costed line, paid on a schedule your cash flow can carry.
2. **Which decisions will you make, and when?**
   In writing. If it is only recruitment, price it as recruitment.
3. **What comes back to your community?**
   Your questions in the bid, findings shared back, credit, and something that stays.

Inclusive research shares all three. In community research, communities hold all three.

WHERE THESE TERMS COME FROM

Participatory action research (Freire; Fals-Borda): research with communities, for change. Community-based participatory research (Israel et al., 1998): an equitable partnership at every stage. Disabled people's and survivors' research: "nothing about us without us". Inclusive research, coined by Walmsley (2001) for research with people with learning disabilities; we use it for the shared side, as defined in The Inclusive Research Collaborative (Rauf, 2026). What they share, in Cornwall and Jewkes' words (1995), is that the difference lies in "the location of power".

KEEP GOING

Read *Community research has to claim power*, Issue 01 of The Interspace Essays, at elysium.london/community-research-has-to-claim-power. Session two of The Interspace Series is planned for January or February 2027. The full reference list is in the session slides.

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